



THRIVE

**Redesigning mental health services
for children and young people**

Healthy
young
minds



THRIVE



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Healthy
young
minds

Executive Summary

The 'Healthy Young Minds' project is aimed at improving how services are delivered to support children and young people's emotional wellbeing and mental health in Lancashire and South Cumbria.

The project has used co-production to involve service users, parents, carers, service providers and commissioners in a collaborative approach to improve how services are delivered through the THRIVE model. (See appendix 2 in accompanying appendices document page 13).

During May and June 2018, local Healthwatch teams from the Lancashire and South Cumbria local Healthwatch Collaborative (referred to as the Collaborative from now on) supported the facilitation of seven co-production workshops at a variety of locations. Healthwatch is an independent public voice for health and social care and exists to ensure that the experiences and views of people who use services are captured to inform service design and to drive improvements.

The 'Healthy Young Minds' project team was aware that current service delivery could be improved and agreed it would be helpful to explore the approach to service delivery and its impact on customers thematically to help the redesign process. The 'Healthy Young Minds' project team reviewed the project mandate and identified key areas/themes where a coproduced solution was required. Each co-production session would focus on a key area/theme. Healthwatch were engaged to support this work.

The key areas/themes agreed were:

- Crisis
- Access
- Transition
- Digital
- Stigma
- 'One stop shop' (multi-themed event) and
- Care of the most vulnerable.

Each workshop was designed to involve stakeholders to consider:

- What is happening now?
- What needs to be fixed?
- What would a great service look like in the future?

Stuart Dunne - working in an independent capacity - and Rachael Ray of Lancashire Mind were responsible for leading important preparation work, working with young people and parents/carers respectively, to help them understand the co-production approach and what would be expected of them at the workshops. These preparation sessions supported individuals to prepare and subsequently present about their experiences at the workshops.

Over 250 young people, family members and other carers - along with health care professionals - attended the seven workshops.

The workshops were designed to be highly participative and themes from each individual workshop were captured at the end of each session and recorded on the website. The work generated a vast amount of information and feedback on paper tablecloths, post-it notes and flip chart paper which is included in full in the appendix to this report. This material has not been academically analysed but instead facilitators agreed key themes at the end of each session which were posted on the project website. Analysis of those session based themes has led to the overarching themes, listed below, which should be taken into consideration during the model design phase.

Participants were asked “what are the top 5 things to fix?”

Overarching analysis suggested:

- There isn't enough support for young people from services
- People in communities and professionals need more knowledge about mental health and its impact
- Waiting times are too long
- Criteria get in the way of accessing support
- There needs to be more options for treatment
- There continues to be a negative stigma about mental health.

Participants were asked to consider “what would a great service look/feel like?”

Overarching analysis suggested:

- Young people would feel that they are supported by services or know they would be supported if they needed help
- Young people would be able to access the service they need when they need it
- Young people would receive the right help at the right time
- Young people would feel that their needs were met all the time
- Young people would feel that services were shaped around their needs at each stage. It would be a truly person-centred service.

This project demonstrated the value of co-production with most people reporting that that they felt listened to. Young people, family members and carers were supported to tell their stories which had a profound impact on participants and motivated those there to think about how to make improvements.

At the end of each session participants were asked to use one word to describe how they felt about their involvement. Some of the key words recorded were:

Hopeful	Optimistic	Positive	Enlightened
Shocked	Cynical	Inspired	Underwhelmed
Excited	Tired	Angry	Upset

At the last event, the following feedback was recorded;

“Good, but they need follow up workshops to understand what action is being taken and to feedback to service users and their families. Some people feel that they have been here before and are just going around in circles”.

Why it matters

Some of the most significant quotes about the approach and subsequent expectations came from the young people and the parents and carers.

Young people's quotes:

- "It's a good way to involve young people - it's good to include young people's experiences"
- "This was interesting"
- "This was a good way to involve young people"
- "Nice people listened, and it was a chance to share my opinion and experience".

Parents' quotes:

- "For the first time, I felt like my opinions mattered" - mother of female aged 16 using CAMHS
- "Sitting in that room with those people and the jobs they do, made me feel important"
- "Wow, the professionals listened to me and valued my opinion" - mother of male aged 14 using CAMHS
- "I suffer from anxiety myself and yet wanted to talk about my story so people who make the decisions can understand what it is like for me and lots of other families".

In conclusion, the THRIVE programme has:

- Made good progress
- Demonstrated an ability to involve people in good co-productive conversations
- Identified key issues to be addressed
- Identified the key criteria for a "great" service
- Raised expectations for improvements
- Provided people with an opportunity to speak, which has had both positive and negative impacts
- Provided a framework for the redesigned model and a mechanism to test its effectiveness.

There is a collective responsibility now to use the wealth of material generated to shape an improved model which can meet the expectations that have been expressed above for a "great" service.



Introduction & Background

A major service redesign project is underway to change the way that children's mental health services are delivered across Lancashire and South Cumbria.

The Lancashire and South Cumbria, Children and Young People's Emotional Well Being and Mental Health Transformation project "Healthy Young Minds" is focused on using co-production to improve how services are delivered and is aiming to shape service delivery around the THRIVE model. The website can be found here: <https://www.healthyyoungmindslsc.co.uk/camhs-redesign>

The team has recognised that services could be better, and this project is focused on improving the model, service delivery and the experiences of those using services.

The current national target is that 35% of young people with a mental health condition should be able to access services funded by the NHS. This can't be achieved by just increasing funding. Effective service improvement is dependent on people, services and organisations working together in partnership to identify the best possible way to make use of available resources.

The aspirations of the team are to:

- Improve waiting times
- Attract more staff to work in services
- Find and close gaps in services
- Make services available for under 5's
- Include 16-18 year olds in children and young people's services rather than adult services
- Develop alternatives to admission.

A key part of the programme has involved a series of co-production workshops designed to bring a wide number of stakeholders together to consider:

- What is happening now?
- What needs to be fixed?
- What would a great service look like in the future?

Co-production involves working together. Co-production is not engagement, involvement or consultation. It does not involve the NHS asking questions and the public replying. It is about working inclusively, listening and creating the conditions for constructive, honest conversations which involve service users, families and carers, providers and commissioners getting together to drive change. NHS England is encouraging the co-production approach and has some resources in place to support this.

<https://www.england.nhs.uk/participation/resources/co-production-resources/>

The role of Healthwatch

Healthwatch is the independent public voice for health and social care and exists to ensure that the experiences and views of people who use services can help to inform service change and improvement. The best way to do this is by carrying out regular engagement activities and collating and analysing the intelligence generated.

healthwatch
Blackburn
with Darwen

healthwatch
Blackpool

healthwatch
Cumbria

healthwatch
Lancashire

Healthwatch has considerable experience of including people in the decision-making processes within the health and care system, championing the importance of lived experience driving change and, in particular, has been involved in developing co-production as a key mechanism to achieve this in practice.

In the light of this experience, Healthwatch Blackburn and Darwen, Healthwatch Blackpool, Healthwatch Cumbria and Healthwatch Lancashire as a Local Healthwatch Collaborative (Healthwatch Collaborative) was asked to independently support the design and facilitation of the THRIVE co-production events taking place in Lancashire and South Cumbria in support of the wider project.

The Healthwatch Collaborative was approached in April 2018 and asked if it would support the co-production part of the work by:

- Providing expert independent guidance based on previous co-production activity to enhance the co-production approach
- Advising on the generic content of the presentation
- Advising about how the sessions should be structured to enhance participation and interaction
- Providing experienced independent leads and facilitators for each session
- Producing a facilitators' brief to clarify tasks and approach for the Healthwatch team for each session
- Providing appropriate workshop resources
- Supporting the debrief process at the end of each session to agree emerging themes
- Reflecting on any further requirements to enhance the delivery of future sessions
- Transcribing all the written materials from paper tablecloths, post-its and flip charts and using this material to produce the final Healthwatch report.
- Presenting the key findings to the Children and Young People Transformation Board.

"We need a better pathway for those children and young people suspected of having autistic spectrum disorder"



Methodology

The plan for this programme was to design, facilitate and evaluate seven events with stakeholders at different locations - each event exploring a different workstream.

It was anticipated that the individual workshops would attract up to 45 people who would identify and share their feedback and ideas. Each event was supported by 2-3 local Healthwatch representatives to provide independent facilitation and by leading NHS staff from the Transformation team to provide technical content and advice.

Young people, parents and carers were being asked to contribute equally in a multi-disciplinary workshop. Preparation for co-production was, therefore, important and sessions were undertaken with young people and parents and carers in advance of the programme to introduce them to the concept and to prepare them to play an active role. This work was led by Stuart Dunne (working in an independent capacity) and Rachael Ray (Lancashire Mind). The preparation workshops identified people who were willing to share their stories at the seven co-production workshops and supported them to prepare for this. The full reports from the preparation sessions are included in the accompanying document of appendices to this report (Appendix 4a and 4b). Extracts from these reports are also included in the sections summarising each session.

In preparation for the workshops the professionals involved similarly needed to be helped to understand how to contribute in an accessible way - for example, no jargon and no job titles were key requests made at the beginning of sessions.

Workshop planning and preparation

The workshop schedule, topics and invitation list had already been agreed prior to Healthwatch being involved, so the Healthwatch role focused on:

- Providing advice on the overall approach and culture for the workshops
- Workshop design to maximise co-production, including the provision of appropriate materials
- Advice on the style and wording of the presentation used at each session. (Note - a generic set of slides was agreed which included a central section which varied according to the topic for each session, see accompanying document of appendices to this report)
- Provision of at least three facilitators for each session
- Developing a comprehensive briefing for facilitators (see accompanying document of appendices to this report) to ensure a consistent approach.

"I need someone reliable and trustworthy to contact, who trusts me and doesn't overreact"

The transformation team's role was to:

- Design the overarching programme of workshops, deciding the focus for each session
- Put in place and support the associated workshops to prepare young people to be able to participate in the co-production sessions.
- Put in place and support work to prepare parents and carers to be able to participate in the co-production sessions.
- Agree the range of participants and send out invitations
- Provide the professional support for each session - in line with the agreed focus of the workshop
- Book the venues and manage all associated logistics.
- Take responsibility for signing-in sheets, development, collection and analysis of session evaluation forms.
- Provide associated communication activity - e.g. updating website

The workshops

The workshops were designed to be as interactive as possible with all participants being encouraged to share and record their thoughts and ideas through the provision of paper tablecloths, post-its and flip chart paper.

Participants were required to sign in at the beginning of the session for fire safety and so we could analyse who had been in attendance. However, for the remainder of the session, participants were asked to identify themselves, not by job title, but simply by name and with a short description of why they were there. Where possible, people were encouraged to mix at tables, but it was also recognised that young people, in particular, sometimes preferred to sit together.

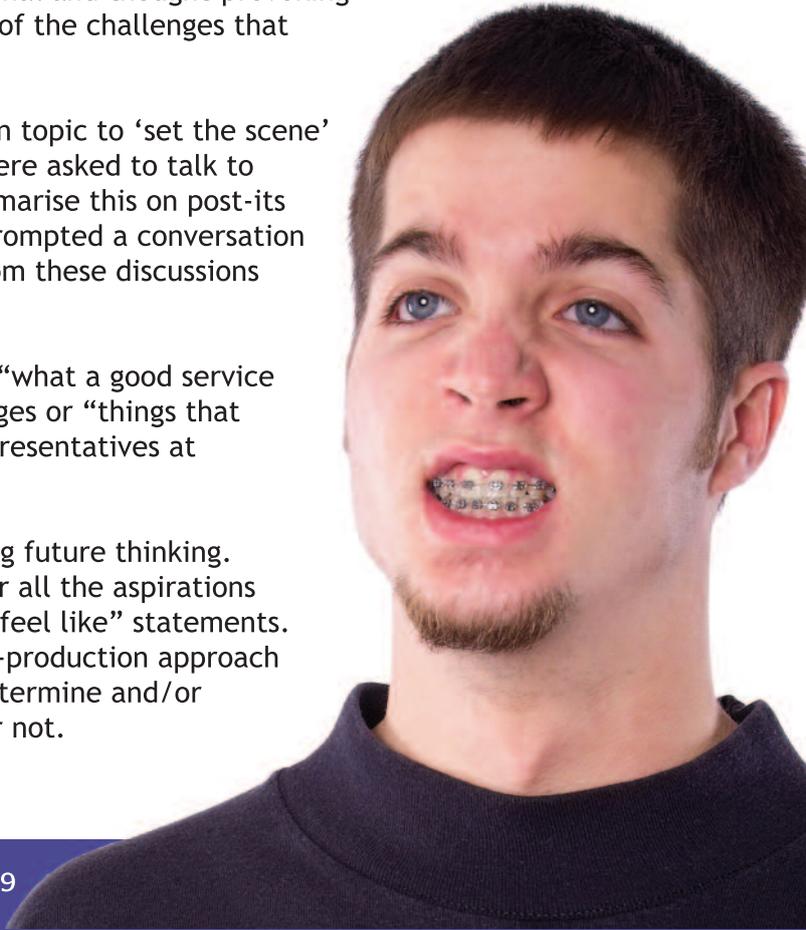
The presentation was used as a framework for the event and included slides on ground rules and co-production to allow discussion on the approach that was being used.

Each session included a presentation from the people who had attended the young people's preparation sessions, led by Stuart Dunne and from those who had attended the family/carers sessions, led by Rachael Ray. These were incredibly powerful, honest, emotional and thought-provoking contributions which, in each case, highlighted some of the challenges that exist in the current system.

Each session then included information on the chosen topic to 'set the scene' for further discussion. Following this, participants were asked to talk to each other about their current experiences and summarise this on post-its which were collated and themed on the wall. This prompted a conversation about "what are we aiming to fix?" and the ideas from these discussions were also recorded.

After this, participants were challenged to describe "what a good service would look or feel like" and if the identified challenges or "things that needed to be fixed" were addressed. Again, the representatives at each table were asked to feedback their thoughts.

This part of the workshop was key in terms of shaping future thinking. A redesigned model would need to be able to deliver all the aspirations described in the "what would a good service look of feel like" statements. The statements would be the test of whether the co-production approach had informed service redesign and would help to determine and/or demonstrate whether people had been listened to or not.



Finally, people were asked to record in a single word, how they felt at the end of the session.

A vast amount of material was generated during each session and people were assured that this would all be recorded and used to inform the development of the delivery model.

Summarising emerging themes and evaluation

Once participants had left each session the Healthwatch team and NHS staff reflected on proceedings and agreed on the key themes and issues which had arisen. These were sent to the communication team to be uploaded onto the website to provide a record of each event and to support people unable to attend the session to keep up-to-speed with developments and provide feedback should they wish.

NHS staff also provided an evaluation form which was analysed separately.

Results from these show that:

- 99.3% of participants felt that the aim of the event they attended was met either fully/to some extent. Comments focussed on what participants liked:
 - “It helped me to understand a little more about what my daughter is going through”*
 - “Everyone recognising the need to work together to improve the service for children and young families”*
 - “Finding solutions to make CAMHS better”*
 - “Timely clear aims”*
- 99.3% of participants agreed that the outcomes for the event were met either fully/to some extent. Comments focussed on what participants liked:
 - “Communication between services”*
 - “Joint thinking”*
 - “Multi-disciplinary, shared experience ideas, some young person perspective”*
- 94.7% of participants found the event they attended to be excellent/good. Comments focussed on what participants liked:
 - “Great mix of professionals from different backgrounds and young people”*
 - “Allowing young people to have their voices heard”*
 - “Very well facilitated”*
- 100% of participants felt that they were listened to all/some of the time. Comments focussed on what participants liked:
 - “That everybody has been listened to”*
 - “Inclusivity”*
 - “Joint thinking”*
- 100% of participants felt that they were heard all/some of the time. Comments focussed on what participants liked:
 - “Sharing news and initiatives”.*

Locations and themes of the events included:

- **Crisis** - Lancaster and Morecambe College, Lancaster
- **Access** - Aspired Futures, Kensington Foundation Resource Centre, Blackpool
- **Transition** - Charnock Farm, Leyland
- **Digital** - Preston Grasshoppers, Preston
- **Stigma** - Aspired Futures, Kensington Foundation Resource Centre, Blackpool
- **One Stop Shop** - Forum 28, Barrow
- **Care of the most vulnerable** - Oswaldtwistle Mills, Oswaldtwistle.

Event 1 - Crisis

Lancaster and Morecambe College, Lancaster
02/05/2018



This was the first workshop and so it had two key roles. First to test the approach, presentation slides and level of interaction with a view to informing the rest of the sessions in the programme and secondly to explore the topic of ‘crisis’ in relation to the development of the THRIVE model. It had been agreed that the debrief session at the end would be an opportunity to reflect on the format so that changes could be made before the next workshop and also to spend time agreeing the key themes and issues for the website.

The invitation list for the workshops was developed to involve people from as many different disciplines as possible. It was good to see that there was a wide range of people who attended, but it was noted that representatives from local authorities were largely absent although they had been invited.

Attendance by Stakeholder Group

Education Sector	1
Healthwatch	1
Local Authority	2
NHSE Commissioner	1
Parent /Carer	1
Provider	14
VCFS	8
Young Person	5
Total	33

+ Information based on signing in sheets. Difference is attributed to the fact that not all attendees signed in .

The Healthwatch facilitator welcomed everyone and asked people to introduce themselves and to avoid using complex job titles or jargon. The young people, parents and carers in the room needed to feel able to contribute equally and the facilitator emphasised that it was important to create the conditions for effective co-production. Agreeing ground rules also helped to reinforce the importance of a co-production approach, as well as providing an opportunity to help to break down barriers to good conversations.

The Healthwatch facilitator set the scene by explaining the purpose of the session, the chosen topic, and by pointing out that this was one of a series of workshops focused on the redesign of children and young people's emotional wellbeing and mental health services.

As explained in the Methodology section, preparation work had already taken place with children, young people their parents and carers. Individuals who had attended these sessions were invited to present to the participants, summarising key themes from these preparation sessions and also telling their story.

In this first workshop, the importance of listening to people's experiences of when things had worked well and more importantly, worked less well stimulated those there to take responsibility for shaping change.

Participants heard from one young person about her challenging journey as she became increasingly unwell, but because she didn't yet meet the criteria for an intervention she became even more unwell before she finally was offered the support she needed.

The young person concerned had since taken responsibility for herself and her continued recovery and was now doing better. She was applauded for her bravery and it was noted that this contribution also helped the other young people present to feel more confident to describe and share their experiences.

The workshop continued to become increasingly interactive - as it progressed - with all contributions being captured mainly by the participants themselves on the tablecloths and post-its. This was important because it meant that their own words were being recorded.

In this workshop and at each of the following events, the value of the preparation work could not be underestimated. We have included in each section (in the blue boxes) a snapshot of the key issues raised within the preparation work for each topic.

"I want to know how to get help, in the right place, at the right time, by the right person"

Summary from preparation workshop on crisis

Setting the scene - what young people have told us already

Crisis - Understanding what it means

- *“I think Crisis is the risk of hurting myself and others, but, I was always at risk of this and got told that I wasn’t”*
- *“There needs to be a clearer definition of Crisis”*
- *“Have better awareness of what a Crisis is”*
- *“I got told to think about the future but why would you think about the future if you don’t feel that you have one, is that a Crisis?”*

Crisis - Potential quick wins

- *“CAMHS needs to define what it means by Crisis”*
- *“Improve communication and training for staff in schools, colleges, in youth clubs and on public transport on what Crisis is and how to help young people”*

Crisis - Future challenges

- *“By the time appointments come around young people are well into a crisis, waiting lists are too long” How can we shorten waiting times or can we provide care in the interim?*
- *“CAMHS needs to recognise the need of the individual, all young people present differently. Services need to take into account additional needs and that they may need a different approach” “One shoe size does not fit all”. So how do we work towards a more person-centred approach?*
- *“Groups need to have access to DBT as is delivered in Preston” How do we ensure that all young people get access to all the services? No postcode lottery.*

Young People’s engagement study case study - Stuart Dunne (See appendix 4a)

Setting the scene - what parents/carers have told us already

- Parents felt that they had the most support when the young person was in crisis
- Parents wanted support in their own homes rather than the young person having to go to a secure unit. The fear from parents was that if their child was in crisis they may never see them again.
- Parents wanted a wraparound approach for the whole family (siblings and grandparents included too). The whole family wanted tools on how to support the young person in crisis which, in turn, may stop the need for Tier 4 services.
- Parents can often spot the signs of their child deteriorating. They felt that they needed to be listened to at this point to prevent escalation.

Parent and Carers’ engagement study case study - Rachael Ray, Lancashire Mind (See appendix 4b)

Crisis Summary

This summary includes the main themes from all of the conversations that were recorded. A complete record of all feedback is in appendix 3 (separate appendices report).

What people want to see fixed

People were asked to consider what needed to be fixed. Feedback highlighted the need for a more proactive approach to avoid people approaching crisis in the first place. They talked about more being done 'upstream' in communities and in schools, about the negative impact of long waiting times and the need for low level interventions which could simply be someone to have a walk with and to talk to. There was a desire for more consistency of staff to support relationship building and trust and a strong theme about the unhelpful nature of criteria.

Key themes for things to be fixed were:

- Be more inclusive
- Get rid of criteria
- Change the culture
- Better equipped staff - training
- Support being available/offered where children and young people are comfortable
- Longer-term support with the same person
- Waiting times are too long
- Knowing where to go for help.

Themes from conversations were:

- Be person-centred - recognising and accepting individuals
- Being taken seriously and being heard
- Voluntary Community and Faith Sector being joined up
- School - coping strategies and prevention
- Support for families, children and young people and schools in a range of ways - listening
- Location - where services are delivered
- Joined-up services around the young person
- Families - skills development for support
- Young people - support in a variety of ways and settings; with a variety of people
- A key theme around 'I will tell you when I am in crisis'
- All services being joined-up and talking to each other
- Earlier access and interventions with children and young people to develop resilience.

Redesigning mental health services for children and young people

These themes were used to consider how a great service would look and feel.
A good service would:

- Have someone reliable and trustworthy in an immediate environment (e.g. school) to contact, who trusts me and doesn't over react
- Have sessions that are comfortable and in less formal clinical settings, where discussing mental health feels normalised
- Be responsive - 'I will get the help when I feel I need it, not only when I fit the criteria of symptoms and situation'
- Involve me - 'No decision for me, about me, without me'
- Ensure all young people will receive a full assessment and access services according to their needs, individually or as a family
- Schools and staff are confident in how to respond to children and young people presenting with distress and/or behaviour issues.

One of the most insightful comments from the workshop was:

"I would know who I could contact and trust to go for a walk with in an open green space when I was feeling low"

More statements of what good would look like are on page 24 in the accompanying appendices document.

Finally, participants were asked to use one word to sum up how they felt at the end of the session.

The most dominant word on this occasion was 'hopeful' and from the young people 'heard' but some people remained sceptical about the extent to which the co-production programme would be effective in informing future service delivery.

"We need to have better commissioning processes, for example, joint commissioning across geographical areas to address the barriers to accessing support"



Event 2 - Access

Aspired Futures Kensington Foundation Resource Centre, Blackpool

09/05/2018



Forty-two people attended this second workshop which had the theme of 'Access'.

The Healthwatch facilitator welcomed everyone and asked people to introduce themselves and to avoid using complex job titles or jargon. The young people, parents and carers in the room needed to feel able to contribute equally and the facilitator emphasised that it was important to create the conditions for effective co-production. Agreeing ground rules also helped to reinforce the importance of a co-production approach, as well as providing an opportunity to help to break down barriers to good conversations.

The Healthwatch facilitator set the scene by explaining the purpose of the session, the chosen topic, and by pointing out that this was one of a series of workshops focused on the redesign of children and young people's emotional wellbeing and mental health services.

Attendance by Stakeholder Group

CCG	1
Healthwatch	1
Local Authority	2
Parent /Carer	5
Provider	8
VCFS	6
Young Person	18
Total	42

Redesigning mental health services for children and young people

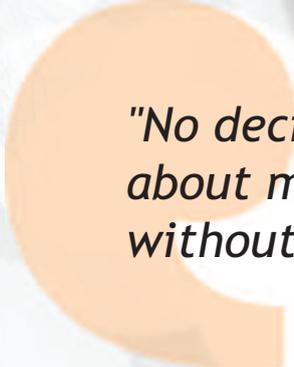
As explained in the Methodology section, preparation work had already taken place with children and young people and with parents and carers. Individuals who had attended these sessions were invited to present to the participants, summarising key themes from these preparation sessions and also telling their story.

As in the first workshop, the importance of listening to people's experiences of when things had worked well and more importantly, worked less well stimulated those there to take responsibility for shaping change.

Participants heard from a young person and a carer. Both shared their experiences around the difficulties they encountered to access the right support in a timely manner. The young person recounted how she didn't feel that professionals took her seriously, which led to her feeling suicidal. The carer spoke of the isolation experienced as a result of not getting early intervention for the young person in her care. In addition, the difficulties that families and carers face when a young person has an unaddressed mental health concerns due to not being able to access the support they need. It was important to hear their personal stories, and this had a profound impact on participants.

It was evident from the workshop that people felt that there was no easy access to early interventions to alleviate distressful situations. A more co-ordinated approach (including schools and wider voluntary community and faith sector support) to help identify early signs of mental health and wellbeing and apply interventions was thought to be beneficial and would enable accessibility for young people who may not easily access mental health services.

The value of the preparation work can not be underestimated, and the blue boxes provide a snapshot of the key issues raised on 'access'.

A quote is presented in a white, italicized font, enclosed within a light orange speech bubble shape. The background of the entire lower half of the page is a grayscale close-up of a young person's face, looking directly at the camera with a neutral expression. The lighting is soft, highlighting the person's eyes and features.

*"No decision for me,
about me,
without me"*

Summary from the preparation workshops on 'access'.

Setting the scene - what young people have told us already

- Young people told us that they not only struggle to understand and navigate the routes to accessing services, but, once referred; they also said that practical access such as appointments also creates barriers to them getting well as quickly as possible.
- *"All I wanted school to do was listen"*
- *"At the GPs I had to say I was suicidal"*
- *"School referred me, but CAMHS said I wasn't ill enough. I was told, I know your saying your suicidal, but I don't think that you will kill yourself"*

Access - Potential quick wins;

- *"CAMHS needs to define what it does and CAMHS needs to promote itself better"*
- *"We need to improve schools understanding of mental health, we need to support schools in identifying young people, we need to increase knowledge about the services already available and we need to increase teacher's awareness of mental health"*
- *"We need to publicise good schools"*
- *"We need to use young people's experiences as stories"*
- *"We need one website that provides clear information on how we can access services"*
- *"We need people to be able to point young people in the right direction"*

Access - Future challenges;

- *"We would like a person to talk to that makes us feel comfortable" How do we get this?*
 - *"We'd like to meet in public places, possibly drop in centres in the town centre" Why can't we do this?*
 - *"We'd like to make self-referral easier" Why is it not easy and can it change?*
 - *"We want waiting times to be cut, don't wait until it's too late"*
- Young People's engagement study case study - Stuart Dunne (See appendix 4a)*

Setting the scene - what parents/carers have told us already

- A common theme was parents had to exaggerate the need at that point to be seen.
- They wished for the service to be more person centred.
- Offer the young person a choice of interventions. One size doesn't fit all.
- There also need to be an offer of appointments times, venues etc. If there was an option, there would be less DNA's (Did Not Attend).
- When a referral is made into CAMHS if you are the right service, make the referral to the right one and get that service to contact the family.

Parent and Carers' engagement study case study - Rachael Ray, Lancashire Mind (See appendix 4b)

Access Summary

This summary includes the main themes from all the conversations which were recorded. A complete record of all feedback is in appendix 3 within the accompanying appendices document.

What people want to see fixed

People were asked to consider what needs to be fixed. The feedback highlighted a need to create an accessible environment for early ‘non-judgemental’ intervention to prevent crisis situations.

Key themes for things to be fixed were:

- Waiting times
- Earlier support
- Choice/flexibility of venue
- Raising awareness of mental health
- Practical solutions for problems - e.g. accessing appointments, being too quick to discharge
- Fragmentation within and between services- lack of care coordination
- Children and young people not being equipped with resilience and self-help skills
- Lack of options to access
- CAMHS seen as the only source of help
- Lack of ongoing support
- Name of ‘CAMHS’ creates a barrier
- Ability to share information between agencies
- Lack of information around options and what help is out there.

Themes from conversations were:

- Communication - inter-organisation communication and communication of services available
- Training - for teachers and problem-solving skills for children and young people
- Waiting times - to access appointments and support
- Consistency - seeing the same members of staff and provision (postcode lottery)
- Environment - community venues, neutral ground
- Volunteering - young people want to volunteer and support each other
- Whole family support - including understanding families practical needs which may prevent access to services
- Co-production - co-produced care at all levels, equal partners in own care.

These themes were used to consider how a great service would look and feel.

One of the main areas of discussion centred around the impact on families when they can’t access the suitable support when they need it.

A good service would:

- Let the young people decide where and when they want it to make them feel comfortable
- Parents would like some level of crisis support at home
- Be safe and confidential - ‘I know my sessions are confidential. I feel safe’
- Right service at the right time by the right people
- Having a meet up beforehand to get to know one another - building positive relationships
- Triage - face to face, telephone
- Helpline out of hours.

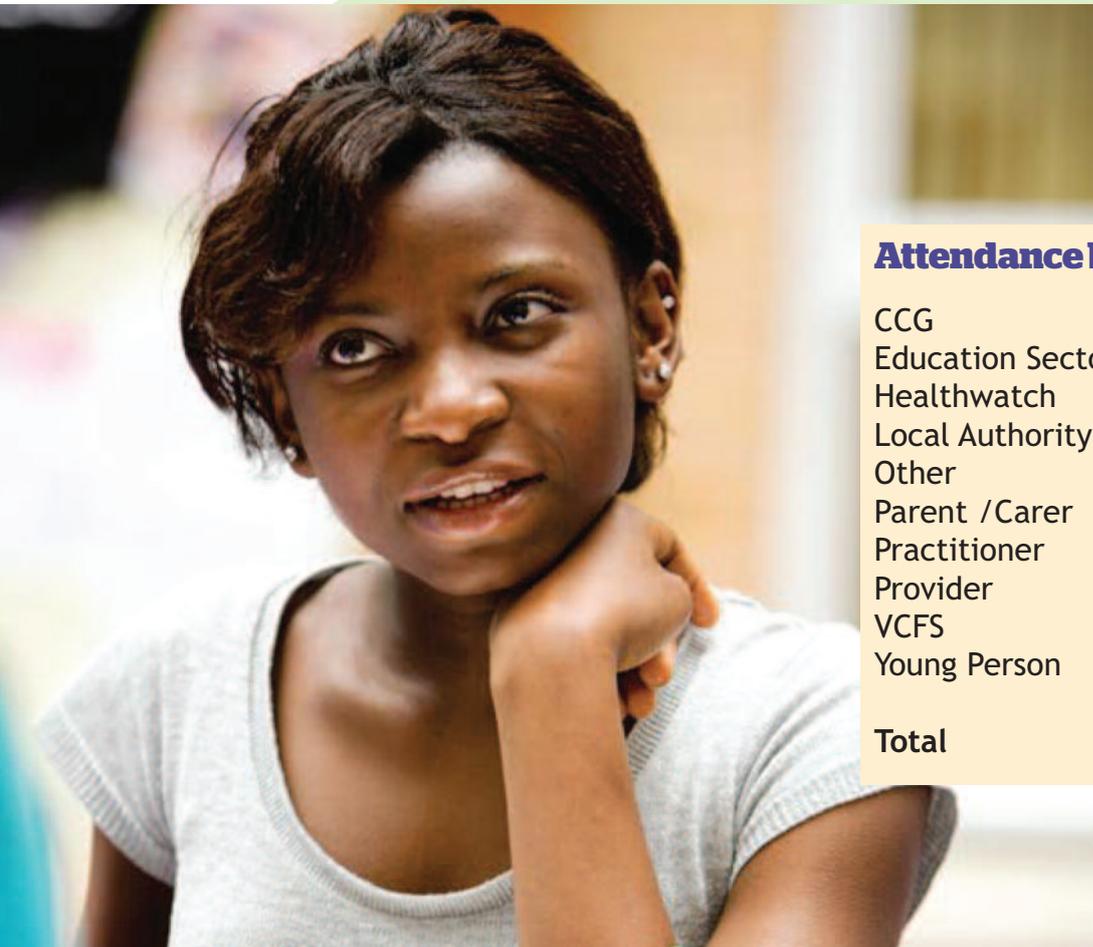
More examples of statements about ‘what good would look like’ are included in appendix 3 in the accompanying appendices document (see page 30).

Finally, participants were asked to use one word to sum up how they felt at the end of the session. The most dominant words on this occasion were “community”, “optimistic”, and “support”.

Event 3 - Transition

Charnock Farm, Leyland

14/05/2018



Attendance by Stakeholder Group

CCG	2
Education Sector	3
Healthwatch	2
Local Authority	3
Other	2
Parent /Carer	1
Practitioner	1
Provider	10
VCFS	6
Young Person	3
Total	33

Thirty-three people attended this third workshop which had the theme of ‘transition’.

The Healthwatch facilitator welcomed everyone and asked people to introduce themselves and to avoid using complex job titles or jargon. The young people, parents and carers in the room needed to feel able to contribute equally and the facilitator emphasised that it was important to create the conditions for effective co-production. Agreeing ground rules also helped to reinforce the importance of a co-production approach, as well as providing an opportunity to help to break down barriers to good conversations.

The Healthwatch facilitator set the scene by explaining the purpose of the session, the chosen topic, and by pointing out that this was one of a series of workshops focused on the redesign of children and young people’s emotional wellbeing and mental health services.

As explained in the Methodology section, preparation work had already taken place with children and young people and with parents and carers. Individuals who had attended these sessions were invited to present to the participants, summarising key themes from these preparation sessions and also telling their story.

As in the first two workshops, the importance of listening to people’s experiences of when things had worked well and more importantly, worked less well stimulated those there to take responsibility for shaping change.

Redesigning mental health services for children and young people

Participants heard from a young person on how concerned she was around transitioning to adult mental health services and the differences in support.

Discussions particularly highlighted the difficulties experienced by young people and their parents around transitioning services. Training needs were identified by staff from both children and adult services in order to adequately support any proposed changes in the model of transition.

The young person who gave the presentation was then involved in gathering the collation of the feedback from the groups and went on to present the key themes during the workshop. This demonstrated a high level of engagement from the young person involved.

The value of the preparation work can't be underestimated, and the blue boxes provide a snapshot of the key issues raised on 'transition'.

Summary from preparation workshop on 'transition'

Setting the scene - what young people have told us already

Potential quick wins

- *"Communication about transition needs to be effective and affective"*
- *"Think about induction days, new services can visit us"*
- *"Workers should accompany us to first meeting".*

Future challenges

- *"Can we investigate a potential cross over between adult and young people's services i.e. young people 0-25 years and adults 18 years plus?"*
- *"In my transition I had a four month wait then six months for first appointment, how do we stop this from happening?"*.

Young People's engagement study case study - Stuart Dunne (See appendix 4a)

- The process has been a poor experience for several the families
- The young person is a child in the eyes of the law and yet not for the service.
- The families felt that the service should be for young people up to the age of 18 as a minimum, 24 ideally.

Parent and Carers' engagement study case study - Rachael Ray, Lancashire Mind (See appendix 4b)

Transition Summary

This summary includes the main themes from all the conversations which were recorded. A complete record of all feedback is in appendix 3 within the accompanying appendices document.

What people would like to see fixed

People were asked to consider what needs to be fixed. Feedback highlighted the need for a seamless transition for young people and a greater understanding and working relationship between children's and adult's mental health services. The role of parents was also highlighted as an area for attention - in particular their continued involvement after transition.

Key themes for things to be fixed were:

- Information to make more informed choices
- 14-25 years window to be flexible about choices
- Good pathway to transition
- Not to have to tell their story every time
- Equal systems to be used
- Consistent prescribing
- Thresholds across adult services within CAMHS
- Consistent policies between services
- Better knowledge between CAMHS and AMHS - staff meetings to share knowledge
- Preparing young people and parents/carers earlier
- Workforce skill competencies.

Themes from conversations were:

- Age range up to 16 in some cases; 18/25 for others (including services provided by VCFS)
- Unclear when transitioning should start
- Referrals at age 15 are told there is no point in CAMHS seeing them
- Referral decisions should include parents/carers as families are still responsible for them
- Parents/carers want to be involved in decisions about their care
- There needs to be clear communication about transition between services and parents/carers
- Young people do not wish to keep telling their stories over and over again
- People feel dis-empowered - CAMHS not wanting to let go
- Adult mental health services (AMHS) not wanting to work with Children and Young People (CYP)
- Parents/carers want to stay involved but cannot 'navigate the system'
- Long waiting lists for AMHS
- Training needed for AMHS staff to work with 16-18 year olds - wasn't focus of workers' training or ongoing CPD
- Based upon chronological age, not based on young person's maturity or need
- Tension around managing adults with severe mental health needs/crisis and managing children and young people
- Signposting - needs to be able to give accurate and correct information.

These themes were used to consider how a great service would look and feel.

One of the main requirements was for an introduction of a seamless transition that could be easily navigated and involved the parents as well as the young person.

"If young people say how they are feeling they shouldn't get judged and pushed away. If they need help, give it to them. You could be affecting their life!"



A good service would:

- Prepare people for transition - 'I feel well prepared for the transition'
- Young person led
- Involve good preparation
- Be informative throughout - 'I received clear information along my journey'
- Manage expectations - 'I knew what to expect, what people said would happen, did happen'
- Enable choice - 'I was made aware of my choices at each step of the way'
- Offer cross system support - young people and parents/carers should receive seamless support without the need to involve them in 'policies and finance'
- Ensure opportunities to get things right before transition
- Continuity of care
- Design services around the individual to meet their needs
- Person enabled to self-navigate
- Know that what is said will happen
- Awareness of choices along the way
- Help other young people with their transition
- A follow-up call once the young person has transitioned out of CAMHS.

Finally, participants were asked to use one word to sum up how they felt at the end of the session. The most dominant words on this occasion were “encouraged”, “shocked”, and “enlightened”, “doubtful” and “underwhelmed”.

Event 4 - Digital

Preston Grasshoppers, Preston

14/05/2018



Attendance by Stakeholder Group

CCG	2
GP	1
Headstart	1
Local Authority	5
Other	4
Parent /Carer	3
Provider	13
VCFS	7
Young Person	8
Total	44

Information based on signing in sheets. Difference is attributed to the fact that not all attendees signed in

Forty-four people attended the ‘digital-themed’ workshop at Preston Grasshoppers on the 23rd May for the fourth event in the series.

The Healthwatch facilitator welcomed everyone and asked people to introduce themselves and to avoid using complex job titles or jargon. The young people, parents and carers in the room needed to feel able to contribute equally and the facilitator emphasised that it was important to create the conditions for effective co-production. Agreeing ground rules also helped to reinforce the importance of a co-production approach, as well as providing an opportunity to help to break down barriers to good conversations.

The Healthwatch facilitator set the scene by explaining the purpose of the session, the chosen topic, and by pointing out that this was one of a series of workshops focused on the redesign of children and young people’s emotional wellbeing and mental health services.

As explained in the Methodology section, preparation work had already taken place with children and young people and with parents and carers. Individuals who had attended these sessions were invited to present to the participants, summarising key themes from these preparation sessions and also telling their story.

As in the previous workshops, the importance of listening to people's experiences of when things had worked well and more importantly, worked less well stimulated those there to take responsibility for shaping change.

Unfortunately, at this event there was no young person available who was able to share their 'story' around their experiences of services - however, there were eight young people who participated in the workshop.

The value of the preparation work can not be underestimated, and the blue boxes provide a snapshot of the key issues raised about 'digital' issues.

Summary from preparation workshop on 'digital'

Setting the scene - what young people have told us already

We asked the question. How can we improve access to digital services for young people?

- *"There is a danger that over reliance on the digital world will lead to a lack of relationships"*
- *"It shouldn't be the only option, it should depend on the individual, digital support should not replace face to face"*
- *"Digital support will be okay for general support but not specialist".*

Potential quick wins

- *"Have a website with staff pictures and names on, so we can see who's who"*
- *"On a website, have information of how young people can voice their opinions, how can young people get heard"*
- *"Use videos to inform young people about what to do, when and who to speak to".*

Future challenges

- *"Skype would be better than through text or Apps, young people don't like Apps as they take up phone storage"*
- *Can we use Skype, or something similar as a complementary method to offering support to young people?*
- *How can the digital world be utilised without making young people feel awkward or that they are being fobbed off?*

Young People's engagement study case study - Stuart Dunne (See appendix 4a)

Setting the scene - what young people have told us already

- *Parents liked the idea of a digital booking system*
- *Online contact details for who to contact and when is also something they discussed.*
- *Online tools or tutorials on how to manage your child or yourself going through this period.*
- *The fear was that this could create a platform where individuals prey on those vulnerabilities.*

Parent and Carers' engagement study case study - Rachael Ray, Lancashire Mind (See appendix 4b)

Digital Summary

This summary includes the main themes from all the conversations which were recorded. A complete record of all feedback is in appendix 3 within the accompanying appendices document.

What people would like to see fixed

People were asked to consider what needed to be fixed. Feedback highlighted the importance of retaining face-to-face contact, although digital technology was identified as playing an important part particularly in supporting early intervention.

Key things to be fixed were:

- Single point of access
- Better preparation for first appointment at CAMHS
- Share information between services
- Increased digital access to support wellbeing
- Better relationships with doctors and counsellors
- Helping people access support
- Helping people get support before they get worse
- More support for parent/carers
- Less barriers getting rid of eligibility criteria
- Terminology and abbreviations making language more accessible and easier to understand.

Themes from conversations:

- Lack of signposting
- More Prevention
- Consistency of Care
- Using the internet to self-diagnose
- Young People are not listened to - self assessment not taken seriously
- Barriers to accessing services - should be the right place at the right time
- Education/training of the workforce to help support young people
- “Un-co-produced, un-helpful, un-personalised”
- Problems with current digital technologies
- Loss of faith in the NHS
- Digital ‘as well as’ not ‘instead of’ - should be the ‘golden thread’
- Stigma - no labels.

These themes were used to consider what a great service would look like:

- Digital to complement face to face not replace it
- Getting reports/people’s stories sent digitally
- Digital is ‘golden thread’ through all the projects
- Drop-in centres to get support with digital
- Online advice on where and how to get help.

This is a summary of the feedback received. For a full breakdown of the feedback around the three key themes, please see appendix 3 in the accompanying appendices document (page 36)

Finally, participants were asked to use one word to sum up how they felt at the end of the session. The most dominant words on this occasion were “excited”, “inspired”, and “people”.

Event 5 - Stigma

Aspired Futures Kensington Foundation Resource Centre, Blackpool

29/05/2018



Entwined Minds @EntwinedM · May 29
 #camhsredesign #reducingstigma #makingadifference



Twenty-eight people attended the ‘stigma-themed’ event at Aspired Futures on the 29th May for the fifth event in the series.

The Healthwatch facilitator welcomed everyone and asked people to introduce themselves and to avoid using complex job titles or jargon. The young people, parents and carers in the room needed to feel able to contribute equally and the facilitator emphasised that it was important to create the conditions for effective co-production. Agreeing ground rules also helped to reinforce the importance of a co-production approach, as well as providing an opportunity to help to break down barriers to good conversations.

The Healthwatch facilitator set the scene by explaining the purpose of the session, the chosen topic, and by pointing out that this was one of a series of workshops focused on the redesign of children and young people’s emotional wellbeing and mental health services.

As explained in the Methodology section, preparation work had already taken place with children and young people and with parents and carers. Individuals who had attended these sessions were invited to present to the participants, summarising key themes from these preparation sessions and also telling their story.

As in the previous workshops, the importance of listening to people’s experiences of when things had worked well and more importantly, worked less well stimulated those there to take responsibility for shaping change.

Participants heard from a young man who talked about using his own experience of addressing the stigma associated with a mental health challenge to help others facing the same situation.

Attendance by Stakeholder Group	
CYP participation group	1
Local Authority	3
Parent /Carer	2
Provider	8
VCFS	6
Young Person	8
Total	28

Information based on signing in sheets. Difference is attributed to the fact that not all attendees signed in

Summary from the preparation workshops on 'stigma'

The value of the preparation work can not be underestimated, and the blue boxes provide a snapshot of the key issues raised about 'stigma'

Setting the scene - what young people have told us already

One potential quick win

- "We need to realise that we will never get rid of stigma but may be able to reduce it", "Mum called me a nutter, it was a joke but it hurt" it is systemic.
- It is about managing Stigma better as we will never eradicate it.

Future challenges

- How do we educate people better about Mental Health? "We have lessons on terrorism but not mental health"
 - How do we improve on the perception of Mental Health Services "Think about rebranding don't use the word mental in any name" "CAMHS needs to promote itself, I didn't know it was there"?
 - How do we ensure that information is "100% true" "explain what an illness is not the symptoms" and how do we "promote real people's stories"?
- Young People's engagement study case study - Stuart Dunne (See appendix 4a).

Setting the scene - what parents/carers have told us already

- This was huge, and the parents and carers felt that the stigma was more of an issue for the parents' generation.
- Parents felt the need for mental health issues to be treated as physical health issues are by professionals needed to be addressed first.
- Parents felt schools often exacerbated stigma by removing the child from school. The police have also been known to treat these young people as an "anti-social behaviour" incident rather than a poor mental health issue.
- Campaigns and professionals from all services working with young people and the wider community have a duty to challenge negative language or behaviours.

Parent and Carers' engagement study case study - Rachael Ray, Lancashire Mind (See appendix 4b)

Stigma Summary

This summary includes the main themes from all of the conversations that were recorded. A complete record of all feedback is in appendix 3 in the accompanying appendices document (see page 41).

What people would like to see fixed

People were asked to consider what needed to be fixed. Feedback highlighted the reluctance of some young people and parents to engage with CAMHS because of the stigma attached to being associated with having a 'mental health problem' and being labelled in this way. People wanted to be viewed in the same way as a person would be viewed with a physical illness.

Words to define/describe stigma:

- Feel dismissed
- Weakness
- Give up
- Patronising
- Lack of caring or empathy
- Confirms negative self talk
- Feel belittled
- Seen as doing it for attention
- Isolating
- Feeling odd
- 'You're not ill enough'
- Being treated as awkward
- Different or difficult (in school)
- Media
- Greater understanding of mental health needed in emergency services and by GPs
- Every child has a right to an education regardless of how they are presenting (it was reported that one young person was 'not allowed' to return to their school after an inpatient admission)
- Appreciate and celebrate diversity
- Incorporate mental health into the school curriculum
- Integrate mental health services into community/existing structures
- Normalise mental health difficulties
- Language change needed - professionals using terms such as 'no mental health' in referral meetings
- Positive media stories/images
- Compulsory education/training for schools and workplaces; parents/carers; teachers and children and young people
- Self-help techniques should be taught in school (terrorism is taught but not mental health!)
- Provision of self help guides for those on waiting lists
- Need more groups in CAMHS with more people participating - knowing that you are not alone
- Changing the name of CAMHS - so no longer seen as a disability
- Everything happens for a reason and people need to realise that and not judge



Themes from the conversations were:

- Change the way people think of mental health
- Better attitude towards mental health
- More money for early help for mental health
- The council show more support - community work together
- 24-hour help - no therapy end date
- MAKE IT COOLER TO BE KIND - rather than being the cool bad guy
- Compulsory awareness sessions in school and the workplace
- Greater understanding from emergency services (Police)
- High schools and colleges need more training in dealing with mental health
- Education - in schools for all children, for adults, teachers, parents
- Developing support network with other young people
- The way people are judging the way they are thinking about a person's personal feature or their looks
- To stop judging people negatively and think more positively about yourself and your features
- Developing support networks with other young people going through same/similar things
- Positive media

What would a good service look and feel like?:

- Found somewhere to 'fit in' and feel worthy of being alive
- It's ok to not feel ok/to be who you are
- We will grow as a society - less unemployment and an accepting culture
- Feel less claustrophobic; walls will be removed; won't feel trapped in a corner or feel like I have no space to move in
- Support being available/offered where children and young people are comfortable
- Knowing where to go for help
- Be myself; no barriers
- Common understanding
- Honesty
- Not having to apologise for who we are and what we are dealing with
- Educating everyone - schools, parents/carers, work
- Social movements
- Language needs to change - negative to positive
- Accept problems rather than reject
- Be able to find people that have the time and the interest
- Established support networks
- Happy that anything is now possible
- Less stressful; no need to explain self over and over again
- Community wrap around
- Education - schools feeling empowered
- Roles of others in recognising and supporting children and young people with a mental health need e.g. police and A&E
- It is not just about the new model - it's about society and individuals

This is a summary of the feedback received. For a full breakdown of the feedback around the three key themes, please see appendix 3 in the accompanying appendices document (page 41).

Finally, participants were asked to use one word to sum up how they felt at the end of the session. The most dominant words on this occasion were "tired", "inspired", and "stressed", suggesting that people find this a difficult topic to discuss but can also see some ideas emerging.

Event 6 - One Stop Shop

Forum 28, Barrow

04/06/2018



Attendance by Stakeholder Group

CCG	2
Education Sector	1
Local Authority	4
Other	4
Provider	22
VCFS	9
Young Person	4
Total	46

Forty-six people attended the One Stop Shop event held at Forum 28 in Barrow on the 4th June for the sixth event in the series.

The Healthwatch facilitator welcomed everyone and asked people to introduce themselves and to avoid using complex job titles or jargon. The young people, parents and carers in the room needed to feel able to contribute equally and the facilitator emphasised that it was important to create the conditions for effective co-production. Agreeing ground rules also helped to reinforce the importance of a co-production approach, as well as providing an opportunity to help to break down barriers to good conversations.

The Healthwatch facilitator set the scene by explaining the purpose of the session. At this event all seven topics were incorporated into the extended event. It was reiterated that this was one of a series of workshops focused on the redesign of children and young people's emotional wellbeing and mental health services.

As explained in the Methodology section, preparation work had already taken place with children and young people and with parents and carers. Individuals who had attended these sessions were invited to present to the participants, summarising key themes from these preparation sessions and also telling their story.

As in the previous workshops, the importance of listening to people's experiences of when things had worked well and more importantly, worked less well stimulated those there to take responsibility for shaping change.

Participants heard from a mother who gave an emotional account about services they had received and the loss of her daughter. It was a difficult story to listen to, but it drove home why co-production is so important. It ensured that those delivering services listened first hand to the experiences of service users and the impact that this has on real people's lives.

One Stop Summary

This summary includes the main themes from all of the conversations that were recorded. A complete record of all feedback is in appendix 3 in the accompanying appendices document (page 47).

This workshop considered all of the topics together and much of the feedback echoed what is recorded for the theme sessions. There was some specific feedback about support, the model of care and staffing and outreach working:

Support

- More mental health awareness events - big football events.
- Looked After Children - need to be able to respond to a large population of 'looked after children' in South Cumbria - as children, as young adults and as they become parents themselves.
- "I agree that more parenting support and mental health awareness is needed but we need to ask parents where and how this is provided"
- Peer support for young people and parents/carers
- Parents should be kept involved - "it's incredibly difficult for a child to say I feel bad, and mental health services should be included in the home - that is where the child spends most of their time".
- "We (parents) have been able to sit in during sessions and talk frankly with counsellor and child. This has been incredibly helpful and helped relieve the guilt that we feel".
- Patient experience team already get a lot of feedback from clients/family.

Model of care

- Clarity on the 'tier' and 'THRIVE' system models.
- Frustrating having to tell story every time to a new psychiatrist/counsellor. Continuity of psychiatrist would be helpful.
- Data sharing/ referrals/transfer of info.
- 'Child/young people friendly' venues and rooms.
- Kooth.com - free online and wellbeing service - offers carers a range of self-help and therapeutic support.
- Is pressure on schools/young people to perform/achieve part of the problem? A focus on academic not social/emotional resilience and early support? Need time to focus on healthy minds not 'passing tests'.

Staffing

- Lack of staff to deliver NICE guideline treatments.
- The CAMHS workers don't want to have to tell people they've got to wait for months. You need to make it better for staff as well as patients.
- Need to recognise how difficult it is to recruit staff in South Cumbria.
- More staff and psychiatrists. Mental health team working with more agencies in community.
- Consider young person's needs and allow CAMHS worker the time to work with more complex cases (this will involve caseload weighting). Not all young people can manage/access/recover with 1 hour of support a week. More complex cases impact on workers jobs - plan allocation.
- Workforce - consistent staff - having different psychiatrist/psychologist at each session saying different things is confusing.

Outreach working

- Staff being matched at assessments/screening stage - consistency of staff for young people. Not having to have an assessment and then effectively start the whole process again 6 weeks later.
- Assessment taking more than 3 sessions with the same worker over set period of time. Support and intervention can be provided, or young person referred to appropriate therapist within service (or stepped-down or discharged).

People were asked to consider what needed to be fixed. Feedback mirrored findings from the previous workshops.

What people want to see changed:

- Families may worry about a 'label' and their child entering services.
- 'Behavioural' schools - stigmatizing and increasing anxiety for those children who have behavioural problems.
- Education is getting better but still stigma in schools and with health professionals
- You get the care in hospital but when you get home there's no support
- Information given out on discharge needs to be geared to young people
- Adult services don't take children and young people's mental health issues seriously enough - we need to work more closely. Child and adult services need to work together to create a family approach to support - not enough emphasis on earlier intervention in adult services.
- How do we support children and young people /families who are 'non-engaging'?
- No service for young people with eating disorders - a 'postcode lottery' for very vulnerable (physical risk).
- Getting support shouldn't depend on having a specific condition.

This is a summary of the feedback received. For a full breakdown of the feedback around the three key themes, please see appendix 3 in the accompanying appendices document (page 47).

Finally, participants were asked to use one word to sum up how they felt at the end of the session. The most dominant words on this occasion were "angry", "upset", "powerless" and "frustration".



Event 7 - Care of the most vulnerable

Oswaldtwistle Mills, Oswaldtwistle

6/6/2018



Attendance by Stakeholder Group

CCG	1
CYP participation group	1
Education Sector	2
Healthwatch	4
Local Authority	2
Other	1
Parent /Carer	2
Provider	14
VCFS	9
Young Person	3
Total	39

Thirty-nine people attended the ‘care of the most vulnerable event’ at Oswaldtwistle Mills on the 6th June and this was the last event in the series.

The Healthwatch facilitator welcomed everyone and asked people to introduce themselves and to avoid using complex job titles or jargon. The young people, parents and carers in the room needed to feel able to contribute equally and the facilitator emphasised that it was important to create the conditions for effective co-production. Agreeing ground rules also helped to reinforce the importance of a co-production approach, as well as providing an opportunity to help to break down barriers to good conversations.

The Healthwatch facilitator set the scene by explaining the purpose of the session. At this event all seven topics were incorporated into the extended event. It was reiterated that this was one of a series of workshops focused on the redesign of children and young people’s emotional wellbeing and mental health services.

As explained in the Methodology section, preparation work had already taken place with children and young people and with parents and carers. Individuals who had attended these sessions were invited to present to the participants, summarising key themes from these preparation sessions and also telling their story.

As in the previous workshops, the importance of listening to people’s experiences of when things had worked well and more importantly, worked less well stimulated those there to take responsibility for shaping change.

Participants heard from a mother who spoke about her experience of her son being hospitalised on a

frequent basis, her difficulties in managing her other children at the same time and the impact this had on her own mental health. She was supported by Lancashire Mind and was grateful to know that someone was there to support her needs. A young man talked about his experience of growing up with asperger's syndrome and his challenges of getting any help from CAMHs as they had no experience of supporting people with autism or asperger's. If it had not been for the support of the charities Action for ASD (Burnley) and Understanding Autism North West (Accrington), then he would have really struggled. He is now starting university in September.

The value of the preparation work can not be underestimated, and the blue boxes provide a snapshot of the key issues raised about 'care of the most vulnerable'.

Setting the scene - what young people have told us already

- *"There needs to be clarity as to what is meant by vulnerable."*
- *"I'm classed vulnerable in one service but not another"*
- *"who judges who is more vulnerable"*
- There was scepticism of why the word is used, is it used as a barrier to stall support?

Vulnerable - Potential quick wins:

- *"Need to meet young people where they want to meet, at a place convenient for them. Somewhere comfortable for young people"*
- We need to recognise that *"Everyone is different and adapt to different situations"*, therefore, can we *"access help out of hours. Have a helpline/ text service. Peer support groups. Group work interventions like DBT"*?

Future challenges

- How do we ensure that *"Help for the vulnerable is joined up between Health, Social Care and substance misuse"* a number of the young people shared personal insights of services not working together? No *"dual support"*
- How do we ensure that *"Parents / carers get support as well?"* Many of them live with our mental health along with us. If they are knowledgeable about mental health, then they can also provide the right support.
Young People's engagement study case study - Stuart Dunne (See appendix 4a)

Setting the scene - what parents/carers have told us already

- We are all vulnerable
- Who decides who is and who isn't vulnerable?
- Campaigns all over the country say you need to talk about mental health, so when we do, we then get told our children aren't vulnerable enough.
- There needs to be clear guidance as to who you access and at what point, with no gaps.

Parent and Carers' engagement study case study - Rachael Ray, Lancashire Mind (See appendix 4b)

'Care of the most vulnerable' Summary

This summary includes the main themes from all of the conversations that were recorded. A complete record of all feedback is in appendix 3 in the accompanying appendices document (see page 41).

What people would like to see fixed

- Need for greater youth and family voice in shaping mental health provision for young people
- Need better knowledge and understanding of mental health
- Need more joined-up working across organisations
- Need better definition of mental health and vulnerability
- Need better continuity of support

What would good look like?

Youth and family voice

- *"I always feel listened to and valued"*
- *"Speak to us in our language"*
- Holistic approach to supporting young people's mental health
- Support groups for young people and parents
- Better support for non-verbal young people .

Better knowledge and understanding of mental health

- *"Everyone is confident and empowered to support young people's mental health"*
- Mental health training for all professionals - including education and youth organisations
- Flexible approach to supporting young people
- Mental health is everyone's business.

Joined up working

- *"Right support at right time"*
- A system of support that is fluid and flexible
- All young people identified for support at earliest opportunity
- Effective multi-agency response and information sharing
- Co-production and co-working on a continual basis.

Defining mental health and vulnerability

- *"Consistency and clarity of definition across all services"*
- Mental health should be self-determined so that families can access the support they need
- Distinguish the difference between feeling low and having mental health issues
- Greater clarity around trigger points for support and how action plans are established based on these.

Continuity of support

- *"Long waiting times will be a thing of the past"*
- Better communication between services
- All services are empowered to signpost young people to other services if they are unable to provide the support they need
- Local support and knowledge available for young people and families
- Seamless transition between different levels of support - if people change the system won't fail them
- A robust system that is locally based.

Evaluation and Conclusion

The THRIVE co-production events have been a success in bringing together health care professionals, young people, families and carers to work collaboratively to redesign children’s mental health services and how they are delivered across Lancashire and South Cumbria.

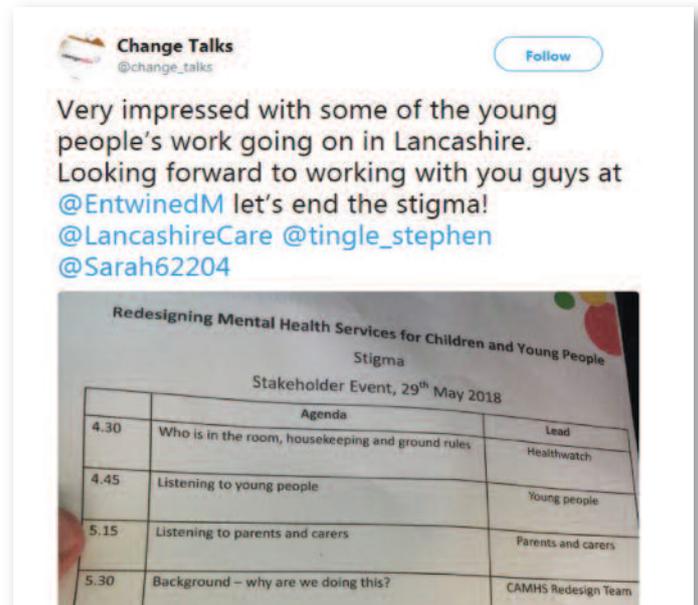
The seven workshops have helped compile extensive feedback from those who use these services on the most important things to focus on at the heart of the redesign.

The work generated a vast amount of information and feedback on paper tablecloths, post-it notes and flip chart paper. This material has not been academically analysed but instead facilitators agreed key themes at the end of each session which were posted on the project website. Analysis of those session based themes has led to the overarching themes, listed below, which should be taken into consideration during the model design phase.

The accompanying appendix document includes all of the written contributions from the workshops and provides a tremendous resource for the design team.

Participants were invited to complete an evaluation form at the end of each event and an independent evaluation team is in place to review the full programme

The onus and challenge now lie with the health care system across the two counties to work to implement these changes to create a better mental health service for young people, designed by young people



"We need to create a CANHbalance!"

TOP FIVE

Things to fix:

- There isn't enough support for young people from services
- People in communities and professionals need more knowledge about mental health and its impact
- Waiting times are too long
- Criteria get in the way of accessing support
- There needs to be more options for treatment
- There continues to be a negative stigma about mental health.

What does good look like

TOP FIVE

- Young people would feel that they are supported by services or know they would be supported if they needed help
- Young people would be able to access the service they need when they need it
- Young people would receive the right help at the right time
- Young people would feel that their needs were met all of the time
- Young people would feel that services were shaped around their needs at each stage. It would be a truly person-centred service.



THRIVE

**Redesigning mental health services
for children and young people**

Healthy
young
minds

healthwatch
Blackburn
with Darwen

healthwatch
Blackpool

healthwatch
Cumbria

healthwatch
Lancashire